



Dementia as a Life-Limiting Illness

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Dementia

- Under-recognised as a life-limiting illness
- In 2020, dementia was the leading cause of death for women, and the second leading cause of death for men, after coronary artery disease (AIHW 2023).
- More than half of all people in permanent residential aged care have dementia (AIHW 2023).



Recognising last months of life

The “Surprise Question”:

*Would you be surprised if this person
were to die in the next 6 to 12 months?*

- Simple screening question
- High sensitivity for the identification of patients with advanced Alzheimer’s Disease dementia (Yuyama et al 2020).



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.



Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:



Nightingale Program:



**Dementia
Australia®**

OFFICIAL

Dementia-specific palliative care support

The Nightingale Program is a palliative model of care, provided by specialist nurses and an Occupational Therapist throughout South Australia for advanced dementia care.

It's available free of charge and provides strategies and advice to support people living with advanced dementia, their families and care providers, with a focus on promoting choice, well-being and forward planning.

The program supports people living at home, in residential aged care and community settings.

How we help

Offering a specialist nurse as the single point of contact, we can develop care strategies to enable people living with dementia to:

- Stay at home longer and maximise their independence.
- Promote quality of life and positive relationships.
- Have a voice in their future care options and decision making.
- Avoid unnecessary presentations to acute hospital settings.
- Have clinical advice including co-morbidity management, pain management, delirium and palliation.

This service is funded by [The Rosemary Foundation for Memory Support](#) and [Country SA PHN](#).

[Download the Nightingale Program brochure](#)

How to access the Nightingale Program

- Call the [National Dementia Helpline](#) on 1800 100 500 or
- Use the online [service enquiry/referral request form](#)



References

Australian Institute of Health and Welfare 2023, *Dementia in Australia*, AIHW, Australian Government.
[Dementia in Australia, Summary - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://www.aihw.gov.au/reports-and-publications/dementia-in-australia)

Hight Get al 2014, 'Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study'. *BMJ Support Palliat Care*. Sep;4(3):285-90.

Supportive and Palliative Care Indicators Tool (SPICT and SPICT-4-All) <https://www.spict.org.uk>

Yuyama et al 2022, 'Palliative Care in Advanced Alzheimer's Disease Dementia: Evaluation of the Answers Given by Caregivers and Physicians to the Accuracy of Surprise Question, as a Prognostic Tool', *American Journal of Hospice and Palliative Medicine*,